

Cystic Fibrosis Research News

Title:

Defining Research Priorities in Cystic Fibrosis. Can Existing Knowledge and Training in Biomedical Research affect the Choice?

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What was your research question?

Allocating funds for research is an uneasy task, and today there seems to be little room left for the expectations of patients. The Patient-Centered Outcomes Research Institute (PCOR-I) recommends conducting research which will lead to evidence-based and patient-centered interventions. The aim of this report is to assess whether research priorities are perceived differently according to a patient's individual knowledge of research topics and their level of training in biomedical research.

Cystic Fibrosis Research News

Why is this important?

Patient empowerment is especially relevant in CF. Much work has been done in the past but it has had little impact on prioritising research issues that are perceived to improve the patients' life. This important goal, however, may be critically dependent on the patient's knowledge of research issues and on the patient's level of training in biomedicine.

What did you do?

There was lack of previous studies, so in 2015 we started testing the above theory with the CF Italian Patient Centered Outcomes Research (IPaCOR) working group.

Four groups of patients and stakeholders were enrolled in this study:

1. Skilled stakeholders, specifically trained in biomedicine;
2. Unskilled untrained stakeholders who responded to a written questionnaire in 2015;
3. Stakeholders who were trained for one year in a course delivered by IPaCOR professionals;
4. Untrained stakeholders who responded to an online questionnaire in 2017.

What did you find?

The ranking of research issues varied greatly across the four groups. Although the research on CFTR modulators gained the highest score across the groups, it was not ranked 1st by any group.

What does this mean and reasons for caution?

Despite several limitations, which include possible bias due to the fact that it is a retrospective 4-year study in groups whose size was not planned in advance and did not include critically ill and paediatric patients, this study may show how it is possible to more closely engage patients and stakeholders in the process of priority setting of research topics; these people may currently be reluctant to be involved in this process due to a perceived cultural inability to cope with biomedical issues. They should understand that they can improve their intellectual capacities and can cope with the recent progress of science. Of course, it is essential that they are informed in the right way. All involved need to play their part in a two-way process exchanging information between patients and stakeholders on one hand, and professionals and clinical researchers on the other. We believe that for research to be meaningful, its methodologic foundation must be scientifically sound and patient-centered. All patients should be able to gauge the quality of research and its usefulness in decision making, by being informed in the right way and working together with all stakeholders, i.e. patients, clinicians and researchers.



Cystic Fibrosis Research News

What's next?

These results emphasize the need to consider the patients' level of education and the delivery of ad hoc training activities by professionals - together with patient's organizations at national and transnational levels - to broaden the knowledge base of patients who may be considered qualified to transfer the PCORI principles into practice.

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